Barriers and Solutions to Linking and Using Health and Social Care Data in Scotland

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Barriers and Solutions to Linking and Using Health and Social Care Data in Scotland

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Abstract

Integration of health and social care will require integrated data to drive service evaluation, design, joint working and research. We describe the results of a Scottish meeting of key stakeholders in this area. Potential uses for linked data included understanding client populations, mapping trajectories of dependency, identifying at risk groups, predicting required capacity for future service provision, and research to better understand the reciprocal interactions between health, social circumstances and care. Barriers to progress included lack of analytical capacity, incomplete understanding of data provenance and quality, intersystem incompatibility and issues of consent for data sharing. Potential solutions included better understanding the content, quality and provenance of social care data; investment in analytical capacity; improving communication between data providers and users in health and social care; clear guidance to systems developers and procurers; and enhanced engagement with the public. We plan a website for communication across Scotland on health and social care data linkage, educational resources for front line staff and researchers, plus further events for training and information dissemination. We believe that these processes hold lessons for other countries with an interest in linking health and social care data, as well as for cross-sector data linkage initiatives in general.

Keywords: Data linkage, health care, social care, integration

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Background

Integration of health and social care is a key priority both within the UK (Scottish Government, 2014*b*) and internationally. Integration of health and social care data is necessary to support effective work practices and evaluation, both at an operational level and for service commissioning and public health delivery; a lack of such data sharing has been proposed as a significant barrier to closer working (Burgess, 2012). There is also growing interest in linking health and social care data for research—evaluation of interventions in one domain (e.g. health care) must take into account effects on other domains (e.g. social care) (Kendig *et al.*, 2012; Lyons *et al.*, 2014).

Here, we report the outcome of a meeting of Scottish stakeholders held in May 2014, which aimed firstly to share Scottish experience in linking health and social care data, secondly to better understand how stakeholders want to use linked data, and finally to map out actions to achieve the above ends. We discuss key themes arising and their relevance to social work practitioners across the UK and beyond. Thirty stakeholders were invited, encompassing social care, health care, university and government sectors, representing service delivery, research, analytic services and policy makers.

Work already underway in Scotland

Brief talks outlined some of the work already taking place, as follows.

Data linkage in Lothian

Dr Rachel Hardie (Consultant in Public Health Medicine) described data linkage in Lothian. Data were successfully linked for 2008–11, with additional linkage planned. Barriers to success included a lack of personnel to work on the linkage, and major challenges remain in understanding and analysing the data. Exemplar analyses around patient pathways, the cost of Chronic Obstructive Pulmonary Disease and effects of a new intervention for hip fracture are being developed.

Data linkage in Tayside

Dr Mark McGilchrist (Senior Research Fellow, University of Dundee) outlined two linkage projects: linking health and social care data in Dundee on people aged sixty-five and over (Witham *et al.*, 2014); and linking health, social care and fire service data on vulnerable adults. Building relationships

with data providers took time, ensuring that data providers retain a say in the use of their data is important in building trust, and deploying external researchers into the social care organisation overcame the lack of resource available to extract and link data. Major challenges remain in understanding how social care data are coded within and across social care organisations.

Scottish Government work

Julie Rintoul (Scottish Government Analytic Services Division) described work being undertaken in collaboration with NHS Boards and local council authorities (Scottish Government, 2014*a*). Yearly snapshots of social care data from twelve social work departments are being linked with health care data held between 2010 and 2014. Planned uses include modelling movement of older people into care homes, improved understanding of costs and improved data on engagement with mental health services. Key challenges to be overcome include disseminating knowledge, increasing analytical capacity, and finding better ways to feedback results to data providers and service users.

Administrative Data Research Centre

Dr Iain Atherton (Lecturer in Nursing, University of Stirling) described the Administrative Data Research Centre (ADRC). This new centre will provide a focal point for social science 'big data' research in Scotland. Staff will have expertise in administrative data and techniques for linkage and analysis to facilitate academic data linkage projects, using anonymised, linked data from different sectors held securely in a safe haven. Exemplar studies will demonstrate potential uses, new ways to utilise data, and mechanisms to retain the confidence of data suppliers and custodians.

Coordinating linkage and data use across Scotland

Professor Alison McCallum (Director of Public Health and Health Policy, NHS Lothian) discussed how to balance individual rights to privacy with the need to measure care quality and improve outcomes. Safe havens are part of the solution, as they allow linkage without disclosure of identifiers, provide a secure environment for analysis and data storage, allow control over who can access the data, and prevent identifiable data from leaving the safe haven. Public confidence in such systems is essential, hence the need for ongoing engagement with the public, with clients and with patients.

Dr Steven Pavis (Head of Programmes, Information Services Division (ISD) of National Services Scotland, NHS) discussed the Scottish Informatics

and Linkage Collaboration (SILC)—an umbrella body for 'big data' initiatives. SILC aims to facilitate this balance between individual and public interest through promoting best practice in anonymised linkage, creating partnerships and networks across sectors (academia, public and commercial sectors) and sharing resources and expertise to create efficient public services.

Group Session 1: What do people want to use linked data for?

Small groups comprising a mixture of disciplines generated ideas on what stakeholders wished to use linked data for. Group ideas were then pooled in a plenary session and key themes were extracted. Table 1 lists the key themes and gives illustrative examples from the discussion.

Other important themes included using linked data to plan services and monitor results of policy changes; to examine inequality in health and social care; to drive integrated cost evaluations; and to identify novel health and social care interventions for future testing. Driving convergence of health and social care culture was mentioned as another potential benefit and, if linked data were available in real time at the operational level, this could significantly reduce duplication and redundancy in assessment of clients.

Group Session 2: Barriers and solutions

Each group was given a single area from Session 1; group ideas were then pooled in a plenary session. Key barriers and solutions identified are listed in Table 2.

Table 1 Suggested potential uses of linked health and social care data

Theme	Example
Mapping trajectories in health and social care	Mapping the trajectory of increasing dependency in older people over time
Refining identification of at-risk populations	People at risk of hospitalisation or care home admission
Evaluation of interventions, especially public health interventions	Data collection to allow evaluation of new service models in social care
Improving data quality in health care research	Social care outcome measures in clinical trials
Building integrated services	Understanding the total need across both health and social care for individuals and groups

Table 2 Barriers and solutions to using linked health and social care data

Barriers	Potential solutions
1. Mapping trajectories in health and social care	
Lack of capacity for complex modelling	Investment encouraging widening capacity, including in academia
Inconsistency in coding of data	Feedback to end users
Lack of understanding of what data mean	Develop common coding 'minimum data sets'
	Clarity—written metadata used in analysis and by data providers
2. Refining identification of at-risk populations	
Insufficient data quality; inaccurate, missing or unavailable data	Feedback from users to data providers to improve data quality
Some prescribing data (especially hospital prescribing) not available electronically	Work required to better understand data availability and limitations
	Electronic prescribing
3. Evaluation of interventions	
Lack of incentives to evaluate properly	Body with teeth required to enforce need for evaluation
Inadequate critical thinking within (national and local) government, National Health Service and the private and third sectors	Guidelines for evaluation, resources
	Commissioned and independently reviewed evaluations
	Engagement of academia—work requires peer review and recognition of academic impact
	Better communication of findings
4. Improving data quality in health care research	
Understanding what data codes really represent	Validate data against gold standards
Inconsistency of data	Build relationships with data providers and users to improve data quality
	Database to feedback issues
	Metadata to describe data
5. Building integrated services	
Consent for data sharing across services	Education—public engagement
System compatibility between services	Standards for data collection and coding
	Single procurement process

Key themes arising from the day

Working relationships across sectors

In order to understand and maximise the usefulness of linked health and social care data, it will be important to communicate with a range of people from multiple sectors and organisations, such as social workers, medical teams, IT professionals, analysts, data protection officers/solicitors and service planners. Working with academia can realise the potential of these linked data, and collaborations need to be built.

Good practice for sharing, linking and analysing data

It is essential that those involved in sharing, linking and analysing health and social care data follow good practice in order to maintain the trust of

service users and the public. Ensuring that the right structures (such as safe havens) are in place, that the right education and training are available and that safeguards are robust but not unduly restrictive is essential.

Improving our understanding of the data

Work is required to better understand what data are available, the quality of data and how the same variables are recorded across different social care organisations. Developing a coherent way of measuring, defining and coding data across health and social care would therefore be desirable. In addition, opportunities exist for extending both the reach of data linkage (to a Scotland-wide system) and the depth of linked data (e.g. adding community nursing records).

Identifying what resources are needed

If organisations wish to utilise linked data to improve evidence around service delivery and research, is the necessary infrastructure and expertise in place for this to happen? Very few analysts have in-depth knowledge of both health and social care, so there is a need to train and support analysts from different sectors to both perform and communicate this work.

Using the data

Better data could also lead to improved evidence for service planning, evaluation and policy development (NHS Scotland, 2014). Analysis based on linked health and social care data should greatly improve our evidence base, such as understanding patient/client pathways, impacts of established interventions and services, researching novel interventions, ensuring staff have the right skills to deal with patient/client needs and informing the spending of public resources.

At present, data linkage does not occur in real time. However, closer working between health and social care teams would be helped by real-time sharing of client-level data. This could facilitate communication; reduce redundancy, delay and error; and bridge cultural differences between health care work and social work. Whilst it would be a mistake to think that data sharing will automatically lead to seamless, smooth, integrated care, it has the potential to assist with this goal. Using aggregate linked data to help solve common problems shared by health and social care is a step along this road.

Dissemination of outputs

Dissemination must encompass a wide range of stakeholders. Feedback to data providers is crucial, as data quality will improve only if providers can see the consequences of their time and effort. Service users and the public should also be included in dissemination plans; analysts and researchers must demonstrate transparent use of data for the public good.

What does this mean for the social worker at the front line?

It is crucial that the voice of front line social work is represented in future efforts to integrate and use health and social care data. Too many IT-driven initiatives have failed to deliver real benefits to the end user (Greenhalgh and Keen, 2013; Cresswell *et al.*, 2012) and a failure to listen to front line staff is often a factor. Despite the challenges (Baines *et al.*, 2014), there are significant benefits that front line social workers can gain from data linkage—easier access to accurate information on clients; more rapid, efficient communication across traditional working boundaries; better information to understand the client base and shape services that are more responsive and better tailored to clients needs, as well as a research base that is better equipped to inform new policy and service development.

To realise these benefits, social workers must be invited to contribute—and the invitation needs to be accepted. Regular feedback to front line staff about current and future projects, plus results of relevance to practice must form an integral part of dissemination strategies; social workers in turn can help to improve data quality and hence the usefulness of outputs by engaging with initiatives to collect accurate, consistent and generalisable data. Although experience of health and social care data integration is limited, examples exist (Bardsley *et al.*, 2011; Australian Institute for Health and Welfare, 2014), which provide a base for further learning.

Conclusions and future work

It is noteworthy that the key themes from the day overlapped with the findings of a previous workshop held to explore social and health care informatics (Rigby *et al.*, 2011). The challenge is thus to implement solutions and four next steps were suggested:

(1) disseminate the results of this meeting to service providers in health and social care, to government and to the research community;

(2) form an interest group, starting with those present at the meeting, to allow pooling of knowledge and skills in this area;

(3) construct a website and resource centre be constructed to provide a focus for information and future efforts in this area, possibly hosted by ADRC;

(4) organise training events, facilitated by ADRC and the Scottish government, on emerging data sets to make the research and service communities aware of what data resources are available.

We believe that the Scottish experience holds lessons for other countries with an interest in linking health and social care data, as well as for cross-sector data linkage initiatives in general, and we look forward to sharing our progress in the near future.

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